

**Responses to a Human Remains Collection:
Findings from Interviews and Focus Groups**

**Prepared for
The National Museum of Health and Medicine**

**By
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EXECUTIVE SUMMARY

This report presents the findings from a study conducted by Randi Korn & Associates, Inc. (RK&A), for the National Museum of Health and Medicine (NMHM), Washington, DC. The study was designed to investigate how visitors respond to the Museum's human remains collection. Specifically, the research objectives were to:

- determine visitors' motivation for visiting the Museum and their expectations of the Museum;
- identify reactions to a range of specimens, including models, illustrations, wet specimens, skeletal specimens, fetuses, and plastinated specimens;
- ascertain what aspects of the human specimens cause visitors to respond as they do to the specimens;
- determine what visitors need to change their initial reactions into learning experiences;
- identify ways to display human specimens and depictions of human specimens so that visitors' experiences include learning.

The summary that follows presents only the most salient findings. All readers are urged to read the report in its entirety, as the verbatim quotations that appear in the body of the report provide context and depth for the larger ideas presented below.

OPEN-ENDED INTERVIEWS: PRINCIPAL FINDINGS

Pre-visit Interviews

Demographic Characteristics

A total of 40 pre-visit interviews were conducted. Both adults (16 and older) and children (aged 10 to 15) who made the decision to visit the Museum were eligible for the pre-visit interview. Of the 40 visitors interviewed, 37 were adults and 3 were children.

Motivation for Visiting the Museum

When interviewees were asked why they decided to visit the Museum, one-quarter (all adults) said they were prompted to visit after seeing a recent television program. One-fifth of interviewees (all adults) had a professional interest in seeing the Museum. Two of the three children interviewed were visiting to fulfill a school assignment.

Expectations about the Museum

Of the 36 first-time visitors interviewed, more than half expected to see specimens. In fact, one-quarter mentioned specific specimens that they hoped to see.

Questions about What Visitors Expect to See in the Museum

Only four of the first-time visitors interviewed had questions about they expected to see. All of the questions related to specimens, and two were about conjoined twins.

Comments Made During Visit

Upon completion of the pre-visit interview, interviewees were asked to carry a notepad into the Museum and to write down any questions or comments that came to mind as they viewed the exhibits. Twenty-six interviewees wrote comments. Nearly all of the interviewees' comments fell equally into three categories: questions about specific specimens or label terms, negative comments about the exhibit methods, and comments about the overall exhibition content.

Post-visit Interviews

Demographic Characteristics

A total of 40 exit interviews were conducted: 20 with adults and 20 with children. The genders for both the adults and children were almost evenly split between males and females. Adults ranged in age from 17 to 53 years, with a median age of 43 years. Children ranged in age from 10 to 14 years, with a median age of 11 years.

Overall Reactions

As interviewees described their overall reaction to what they saw in the Museum, most adults and children talked about specimens. Some were struck by the nature of the specimens: namely, that they were of natural origin. Others were intrigued by specific specimens, such as the normal and pathological fetal specimens and the elephantitis leg.

When asked to compare what they saw in the Museum with what they thought they would see, more than half of the adults and children said the Museum had met their expectations. Many of these visitors had been prepared by friends, family members, or colleagues who suggested that they visit the Museum. Slightly less than half of adults and children were surprised by what they saw. Many were impressed with the number and nature of the specimens in the exhibition. A few had expected a larger facility, having visited the Museum when it was located on the Mall.

Different Reactions to Different Types of Specimens

Although interviewees were asked to discuss the different reactions they had to the different types of specimens in the exhibition, many interviewees began describing their responses to specific specimens. Most of the adults and children talked about the fetal exhibit as awe-inspiring and emotionally evocative or as educationally valuable.

Because interviewees did not initially differentiate their reactions to the various kinds of specimens, they were asked a series of follow-up questions. In response, all of the interviewees thought bones were appropriate for display in the Museum. Similarly, all of the adults and all but one child considered wet specimens acceptable for public viewing. In terms of images that show patients' faces, again, all of the adults and all but one child felt they were appropriate for

exhibition. A few adults, however, said they preferred seeing actual specimens rather than images.

Disturbing Specimens

When asked directly whether they found any specimens disturbing, most of the adults and children did not think anything in the Museum was disturbing. Some of the adults emphasized that visitors to a medical museum should expect to see human remains on display; others thought the word “disturbing” was too negative, preferring to describe specimens as “interesting” or “realistic.” In contrast, two adults and two children found the fetal specimens disturbing, and two adults found the hairball “nauseating.”

Questions Visitors Had about Specimens

Some interviewees had questions about the specimens they saw in the Museum: which specimens were “real” and which were plastic models. A few others had questions about the donors of the fetal specimens and the means through which the Museum acquires specimens.

Educational Mission of the Museum

Interviewees were asked what the Museum could do to help visitors have an educational experience. Nearly all of the interviewees thought that the Museum, for the most part, was already providing this. To further promote education, interviewees had several suggestions: write the labels for the general public rather than specialists, exhibit additional healthy specimens for comparison with the pathological ones, include more health-related topics rather than pathological ones, and discuss disease prevention.

Children in the Museum

Overall, the children interviewed and their accompanying parents thought the Museum was appropriate and educational for children. As stated earlier, only two children had negative reactions to the specimens. One of the parents whose child found specimens disturbing, admitted that she should have prepared her child for the experience.

Opinions about the Museum

Throughout the interview, several interviewees questioned why the study was taking place and expressed concern that the Museum would change its exhibitions. These adults stressed the centrality of the specimens to their experiences at the NMHM.

FOCUS GROUPS: PRINCIPAL FINDINGS

Demographic Characteristics

A total of 20 individuals participated in the two focus groups. The genders were evenly split between males and females. The mean age of participants was 46 years, with one-third of participants aged 45 to 54. Half of the participants had children between the ages of 10 and 18 years. All of the participants had visited a natural history museum at least once in the past two years.

There were two noteworthy differences between the two focus groups. Half of the participants in the second group were African American, while only one African American was present in the first group. Most of the participants in the second group had children between the ages of 10 and 18 years, compared with only a few participants in the first group.

Overall Reactions to a Human Remains Collection

To provide context for the focus group discussion, slides of the Museum were shown, and participants were reminded that the Museum's collection includes human remains. Participants were then asked to discuss why a museum might collect human specimens and what, if anything, the general public could learn from the display of such collections. After participants expressed their views, a statement, prepared by the Museum about its history and mission, was read.

Reasons for Collecting Human Remains

Both focus groups thought a museum would collect human remains specimens for educational reasons. Most participants emphasized that the collection could be used to educate the general public, but some also acknowledged it could be used for research purposes.

Reasons for Displaying Human Remains

Participants thought the public could learn about the human body and the effects of unhealthy behaviors from seeing human remains specimens. A few also felt that seeing such a collection might encourage children to pursue a medical career.

Reactions to Specimens

After the Museum staff uncovered 12 specimens from their collection, the facilitator read a description of each one. Participants were given time to view the specimens and to write down any questions they had about them. A discussion about their reactions was then initiated. After describing their initial impressions, participants were asked to describe whether the natural origin of some specimens affected their response, to identify any specimens they found disturbing, and to compare several pairs of specimens.

Initial Reactions

Overall, both groups were impressed with the specimens, often remarking on their natural origin and wondering about the patients. The first group, however, engaged more readily with the specimens than the second group did, as they asked questions about preservation techniques and were better able to decipher visually complex specimens.

Reactions to Specific Specimens

As participants continued to discuss the specimens, they began making comparisons among them. In addition, some specimens proved to be particularly evocative for participants: both groups found the fetuses compelling; the first group made personal connections to the brain specimens

and head section; the second group had negative associations with the photographs of the man with syphilis.

Natural Origin of the Specimens

Both groups thought the natural origin of the specimens made them more powerful than images. Furthermore, knowing the origin made participants conscious of the specimens' human element. Because of the power the specimens, some in the first group stressed the importance of being prepared before viewing them.

Disturbing Specimens

Nearly all of the participants did not find any of the specimens disturbing. Rather, they felt their experience with the specimens was educational.

Comparisons between Specimens

As participants talked about five designated specimen pairs, their preferences for different specimen types and specific specimens became apparent. Overall, participants found the specimens and the photographs more engaging than the illustration or model. However, participants found meaning only in those specimens that they could visually decipher.

Interpretation of Specimens

After participants discussed the specimens, they were asked a series of questions about how the specimens should be interpreted by the Museum. They were then given six interpretive labels on which to comment.

Information to Accompany Specimens

Participants find comparisons between healthy and pathological specimens useful. Furthermore, they emphasized the importance of having information about current medical advancements and personal information about patients and specimen donors provided.

Responses to Interpretive Labels

Overall, participants responded positively to the interpretive label text. In particular, participants appreciated the personal information about the patients and donors and the description of platination. For some of the specimens, however, participants thought an explanation of the specimen itself was needed; for other specimens, they felt additional patient information would be helpful.

Barriers to Visiting

As the final discussion topic, participants were asked to talk about any barriers they would prevent them from visiting the Museum. Many participants in both groups felt encouraged to visit the Museum after seeing the specimens.

Perceptions of Walter Reed Army Medical Center

Participants in both groups saw the location of the Museum as the primarily barrier to their visiting.

Appeal of the Museum

A few participants thought that the Museum's medical content would be a barrier for some potential visitors. However, only one participant said that the content bothered her.

Appropriateness for Children

Most of the participants who have school-aged children thought the specimens would be appropriate and educational for them. A few questioned whether the Museum was appropriate for elementary school-aged children.

DISCUSSION AND RECOMMENDATIONS

Overall, interviewees and focus group participants thought the Museum's human remains collection was awe-inspiring and educational. The specimens are central to visitors' expectations and experiences at the Museum.

Interviewees and focus group participants did not react negatively to any particular type of specimen. Nearly all of the interviewees thought the whole range of specimens (e.g., bones, wet specimens, models and images that show patients' faces) were appropriate for display in the Museum. They found the specimens of natural origin to be particularly compelling. In fact, knowing that a specimen was "real" influenced whether they attended to it. Similarly, focus group participants were intrigued by the different types of specimens and by the natural origin of the specimens. They did, however, question an illustration, because they felt a drawing was less authentic than specimens or photographs. They also remarked on a few specimens that they could not visually decipher, suggesting that specimens can only be meaningful when visitors can first identify what they are seeing. Participants noted that one strategy that helped them interpret specimens was showing comparisons between healthy and pathological ones.

When asked directly whether any of the specific specimens were disturbing, again, most of the interviewees and focus group participants were not troubled by any of them. The few who were talked primarily about the fetal specimens, wondering about how the Museum acquired them and commenting on the evocative nature of the fetuses themselves. They thought the inclusion of interpretation (e.g., medical information) would make the fetuses less disturbing. It is important to note, that many of the interviewees and focus group participants valued seeing the fetal exhibit and found both the normal and pathological specimens to be powerful examples the complexity of human development.

Interviewees and focus group participants, in general, thought the Museum was an educational place. Focus group participants had a basic sense of why the Museum collects and displays human remains (i.e., for educational purposes), and even those interviewees who had come to the Museum to see the icon exhibits found their experience educational. Moreover, nearly all of the interviewees and focus group participants thought the Museum was appropriate for its target audience of adults and children (10 years of age and older). Some emphasized that parents and the Museum share a joint responsibility in preparing children for their visit and also in providing explanations for what they see.

- Continue to display a variety of specimen types. Participants' responses suggest that with proper labeling and context all specimen types, even controversial ones such as the fetuses, are appropriate for exhibits.
- Consider explicitly stating that the specimens are of natural origin throughout the exhibition, particularly for the plastinated specimens.
- To reinforce the natural origin of the specimens and satisfy visitors' curiosity, consider developing an exhibit that explains how specimens are prepared and preserved.

- Museum visitors may need help deciphering the appearance of specimens. When explaining specimens in label text, use direct references to observable characteristics. Also, include additional comparisons between healthy and pathological specimens.
- Illustrations and teaching models can be used to help explain specimens; however, they will most likely be far less attractive to visitors than actual specimens.
- When faces of patients are depicted in photographs, illustrations, or models, provide a basic patient history and some historical context. For example, describe who the person was, the nature of his/her condition, and the outcome of the condition.
- Labels for the fetal specimens will need to be carefully constructed and would benefit from formative evaluation. Rather than highlighting patient information for these specimens, consider placing the fetuses in historical and medical context. This approach proved somewhat successful with the focus groups.
- Consider developing a more extensive introduction area in the Museum to conceptually orient visitors and to provide parents with information about the collections so that they can plan their visit according to their child's developmental level.
- Until changes can be made to the exhibition, consider developing a gallery guide. The guide can provide context and background information for the icon exhibits (e.g., the elephantitis leg, the hairball, the conjoined twins) to take advantage of the immediate 'hook' that these exhibits have while also turning the initial response into a learning experience.

INTRODUCTION

This report presents the findings from a study conducted by Randi Korn & Associates, Inc. (RK&A), for the National Museum of Health and Medicine (NMHM), Washington, DC. The study was designed to investigate how visitors respond to the Museum's human remains collection. Specifically, the research objectives were to:

- determine visitors' motivation for visiting the Museum and their expectations of the Museum;
- identify reactions to a range of specimens, including models, illustrations, wet specimens, skeletal specimens, fetuses, and plastinated specimens;
- ascertain (within the limits of research that is dependent on participants' subjective interpretation of their reactions) what aspects of the human specimens cause visitors to respond as they do to the specimens;
- determine what visitors need to change their initial reactions into learning experiences;
- identify ways to display human specimens and depictions of human specimens so that visitors' experiences include learning (e.g., understanding that the Museum's human specimens are used to study disease and that collecting and studying human specimens over time is valuable, as well as having a revelation about their own body and how it works).

METHODOLOGY

Methodological decisions are driven by the questions that one has about a topic and the particular nature of the topic (Patton, 1986)¹. The research questions for this study focus on the public's response to the human remains collections at the NMHM. Because the collections are extraordinary and difficult to describe using only the written word, the research methodology incorporated opportunities for participants to respond directly to specimens and artifacts and to express themselves without being confined to predetermined response options (like those that appear on a standardized questionnaire). Thus, two qualitative methodologies were employed to understand public opinions and attitudes about displaying human remains in exhibitions: focus groups with non-visitors and open-ended interviews with Museum visitors.

Open-ended Interviews

Open-ended interviews with Museum visitors, both adults (16 years or older) and children (10 to 15 years old), were conducted. Such interviews were chosen as the best methodology for understanding visitors' experiences with the collection, as currently exhibited in the Museum. In general, the purpose of conducting open-ended interviews is to encourage and motivate interviewees to express their opinions and feelings in their own words, recollect memories and associations, and share with the interviewer thoughtful responses to complex questions. Open-

¹ Patton, Michael Quinn. 1986. *Utilization-focused Evaluation*. Sage Press: Beverly Hills.

ended interviews produce data rich in information because interviewees talk about their experiences from a very personal perspective, including why they think and feel a certain way.

A total of 80 interviews were conducted: 40 pre-visit interviews and 40 post-visit interviews. The target population for all of the interviews was walk-in visitors (not associated with a tour group or special event) 10 years of age or older. Interviewees were selected using a continuous random sampling method. According to this procedure, an interviewer approached the first eligible visitor to enter or exit the Museum, inviting her or him to participate in the study. When the visitor completed the interview, she or he was thanked for participating, and the interviewer awaited the next eligible visitor.

For the pre-visit interviews, when an adult pair or family group was intercepted, the person who initiated the visit to the Museum was selected for the interview. To select interviewees for the post-visit interviews, data collectors used a continuous random sampling procedure but alternated between targeting an adult (16 years or older) and a child (10 to 15 years, with parental consent). Thus, half of the post-visit interviews were with adults and half were with children.

RK&A prepared the pre-visit interview guide (Appendix A) and the post-visit interview guide (Appendix B). The interviews were conducted in the lobby of the NMHM in February and March of 1999. All interviews were tape-recorded with participants' knowledge and transcribed to facilitate analysis.

Focus Groups

Two focus groups with potential adult visitors were convened. Focus groups are a qualitative research method in which a limited number of participants engage in roundtable discussions about topics presented by a facilitator. The focus group methodology was selected as the best method for exploring and understanding potential visitors' reactions to the Museum's human remains collection. Focus groups are most useful for uncovering attitudes, thoughts, opinions, and knowledge about a particular issue. Furthermore, they indicate the "why" behind people's attitudes, and the emotional tone and intensity of a group discussion can demonstrate how strongly participants feel about a given issue. The social nature of focus groups is also an important aspect of the methodology, as it mimics the social setting in a museum—where visitors often discuss with each other what they see and experience. While focus groups present a forum for understanding people's perceptions of issues, they may not yield depth of information. However, they can provide planners with general information about their audience vis-à-vis the issues at hand and also offer a platform for introducing actual objects (e.g., specimens) and discussing opinions and responses to those objects.

Focus group participants were professionally recruited by Metro Research, a market research company. A screening questionnaire was used during the telephone recruitment to ensure that participants had visited two museums in the last two years and, specifically, a natural history museum at least once in the last two years. The focus groups were held at Metro Research in April 1999, with each lasting two hours. Both groups were audio-taped with participants' awareness, and transcriptions were produced to facilitate analysis. RK&A was responsible for

preparing the focus group screener and script (see Appendices C and D), facilitating the groups, transcribing the tapes, analyzing the data, and preparing a summary report.

DATA ANALYSIS AND METHOD OF REPORTING

The data presented in this report are qualitative, meaning that results are descriptive, following from the conversational nature of the interviews and focus groups. In analyzing qualitative data, the evaluator studies the responses for meaningful patterns. As patterns and trends emerge, similar responses are grouped together and interpreted. Following the qualitative tradition of data reporting, trends and themes within the data are presented from most frequently to least frequently occurring.

Verbatim quotations (edited for clarity) are provided in this report to illustrate participants' thoughts and ideas as fully as possible. Within quotations, an asterisk (*) signifies the start of a different speaker's comments, and the moderator's or interviewer's remarks appear in parentheses. Each quotation from the interviews ends with an identification of the speaker's gender and age. Each excerpt from the focus groups ends with an identification number (i.e., the first group is identified as [1] and the second group as [2]). Readers will also note that in the quotations the specimen names appear in brackets. This is because during the focus groups participants referred to the specimens by number, and these numbers have been replaced with the appropriate specimen name.

The study's principal findings are presented in two sections as follows:

- I. Open-ended Interviews
- II. Focus Groups

I. OPEN-ENDED INTERVIEWS: PRINCIPAL FINDINGS

PRE-VISIT INTERVIEWS

A total of 40 pre-visit interviews were conducted in the lobby of the NMHM in February and March of 1999. Of the 42 visitors who were approached, 2 declined to participate. Thus, the refusal rate was 4.8 percent, a very low refusal rate for museum surveys.

Demographic Characteristics

Both adults (16 and older) and children (aged 10 to 15) were eligible for the pre-visit interview. When intercepting visitors in family groups, the interviewer would ask to talk with the person who made the decision to visit the Museum.

Of the 40 decision-makers interviewed, 37 were adults. As Table I.1 shows, more than half of the adults were female ($n = 21$) and less than half were male ($n = 16$). They ranged in age from 18 to 76 years, with most being between 18 and 44. The mean and median age of adults was 35 years.

The remaining three decision-makers interviewed were children (see Table I.2). Two of the children were female and one was male. All three were 13 or 14 years of age.

Table I.1.

Demographic Characteristics of Adults ($n = 37$)

Gender	<i>n</i>
Female	21
Male	16
Age	<i>n</i>
16 - 24	9
25 - 34	9
35 - 44	12
45 - 54	2
55 - 64	4
65 +	1

Table I.2.

Demographic Characteristics of Children ($n = 3$)

Gender	<i>n</i>
Female	2
Male	1
Age	<i>n</i>
13	1
14	2

Motivation for Visiting the Museum

Interviewees were asked why they decided to visit the Museum. Because the timing of the interviews coincided with a television program that featured the Museum, it is not surprising that one-quarter of interviewees (all adults) said they had recently learned about the Museum from this source. One-fifth of interviewees (all adults) had a professional interest in seeing the Museum: they were either physicians or medical researchers who had heard about the Museum from colleagues or from references in their field's literature. Two of the three children who were interviewed came to the Museum to fulfill a school assignment.

Table I.3.
Reasons for Visiting the Museum (*n* = 40)

Reason	<i>n</i>
Heard about the Museum on a television program	11
Professional interest	8
Heard about the Museum from a tourist publication	5
To show a child or friend the Museum	5
To see "medical oddities" and/or specific specimens	4*
Looking for something to do	4
School project	3**

*Includes the response of one child interviewee

** Includes the responses of two child interviewees

Expectations about the Museum

Of the 40 visitors interviewed, 36 were visiting the Museum for the first time. These interviewees were asked to describe what they expected to see in the Museum (see Table I.4). More than half of these interviewees expected to see specimens. In fact, one-quarter mentioned specific specimens: the "Siamese twins" (6 interviewees, including one child), the Lincoln bullet (2 interviewees), "the Elephant Man" (1 interviewee), and General Sickle's leg (1 interviewee). Interestingly, the two children who were visiting the Museum for a school project were not sure what they were going to see in the Museum.

Table I.4.
First-time Visitors' Expectations about the Museum's Exhibitions (n = 36)

Exhibition/Item	n
Specimens	20
Specific specimens (10)*	
“Medical oddities,” “anomalies,” pathological specimens (6)	
“Real stuff” (4)	
Medical equipment, surgical tools, microscopes, the “Iron Lung”	5
Not sure what to expect	4**
“Medical advances,” history of medicine	3
Civil War medicine	2
AIDS Exhibition	2

* Includes the response of one child interviewee

** Includes the responses of two child interviewees

Questions about What Visitors Expect to See in the Museum

The interviewees who were first-time visitors to the Museum were also asked if they had any questions about what they expected to see. Three adults and one child had questions. They are listed below.

I wanted to know how you got the ‘Siamese twins’. [male, age 13]

Is it [the exhibition] mainly reading material or specimens? [male, age 34]

It’s all real, isn’t it? [female, age 28]

Do they still have the ‘Siamese twins’? [male, age 22]

Comments Made During Visit

Upon completion of the pre-visit interview, interviewees were asked to carry a notepad into the Museum and to write down any questions or comments that came to mind as they viewed the exhibits. Of the 40 interviewees, 26 wrote comments, 11 left their notepads blank, and 3 declined notepads.

As Table I.5 shows, nearly all of the interviewees’ comments fell equally into three categories: questions about specific specimens or label terms, negative comments about the exhibitry methods, and comments about the overall exhibition content. Excerpts from the notepads are provided for each category to exemplify interviewees’ responses.

Table I.5.
Interviewees' Written Comments (n = 26)

Comment	n
Questions about specific specimens or label terminology For example: • “How are the leeches used after surgery today?” • “What’s the purpose of the iron lung? How does it work?” • “What is a ‘leprous’ lung?” • “What is ‘trephering’ [sic]?”	8
Negative comments about the exhibitry methods For example: • “Some exhibits need better lighting.” • “Exhibits could be raised more to eye-level—lots of kneeling and bending required—hard on knees and legs.” • “Many exhibits were inoperable or missing.”	7
Comments about the exhibition content For example: • “I think there should be a warning/age suggestion on some of the stuff.” • “There are too many microscopes.” • “There needs to be more information about tuberculosis.” • “I expected a bigger <i>Human Body/Human Being</i> exhibit.” • “Several items that used to be on exhibit are not present, such as the complete nervous system stretched on a frame and the mummified young boy in a ‘Buster Brown’ suit. Where are they?”	7
Unique comments • “How about adding a gift shop?” • “I really enjoyed my visit today. I will visit again.”	4

POST-VISIT INTERVIEWS

Demographic Characteristics

A total of 40 exit interviews were conducted at the Museum in February 1999: 20 with adults and 20 with children.² Of the 43 visitors who were approached, 3 declined to participate. Thus, the refusal rate was 7.0 percent, a very low refusal rate for museum surveys.

As Tables I.6 and I.7 show, the genders for both the adults and children were almost evenly split between males and females. Adults ranged in age from 17 to 53 years, with a median age of 43 years.³ Children ranged in age from 10 to 14 years, with a median age of 11 years.

Table I.6.

Demographic Characteristics of Adults (*n* = 20)

Gender	<i>n</i>
Male	11
Female	9
Age	<i>n</i>
16 - 24	2
25 - 34	4
35 - 44	5
45 - 54	9

Table I.7.

Demographic Characteristics of Children (*n* = 20)

Gender	<i>n</i>
Female	11
Male	9
Age	<i>n</i>
10	8
11	4
12	4
13	2
14	2

Overall Reactions

When interviewees were asked to describe their overall reaction to what they saw in the Museum, most adults and children talked about specimens. Some were struck by the nature of the specimens: namely, that they were of natural origin (see the first and second quotations below). Others were intrigued by specific specimens. Several mentioned the fetus exhibit, commenting on both the normal and pathological specimens (see the third and fourth quotations), and a few talked about the elephantitis leg (see the fifth quotation). In addition to talking about specimens, some adults and children mentioned the bullet that killed Lincoln as an impressive artifact. A few other adults praised the Museum for its extraordinary microscope collection.

[The Museum] was pretty interesting. I like the fact that there [are] real specimens [in the exhibit]. It's not just plastic models—I mean it's real. And the [diseased] state is

² When the post-visit interviews were conducted, the pathological fetus exhibit was on display.

³ Because the frequency distributions of the ages do not follow a bell-shaped curve, the median (middle value) is reported instead of the mean (average), for both adults and children.

always more interesting than the normal state. It's kind of cool to see a tumor. I mean, it's kind of gross, but it gets your attention. [*male, age 53*]

I think the Museum's very good because I can relate a lot of [its exhibits] to my biology class and [that helps me] understand stuff [from class]. . . . [The Museum] not only shows me examples, but also the real thing. Here [at the Museum] I got to see what stuff inside [my body] really looks like. [*female, age 12*]

[The Museum] was really interesting. (Was there anything, in particular, that you found interesting?) I liked the fetus area. I have kids of my own and I just liked seeing how they [the fetuses] developed. [*female, age 42*]

[The Museum] was interesting. I liked the 'Siamese twins' and the 'cyclops'. (Why did you find those interesting?) It was unusual—not something you normally see. [*male, age 42*]

I liked to look at the abnormal bone growths and the elephantitis stuff. Pretty wild. (What in particular was intriguing about that?) Just different facets of what the human body can do, what it can become, the abnormalities of the human body that we just don't even think about. It's very interesting. [*female, age 23*]

When asked to compare what they saw in the Museum with what they thought they would see, more than half of the adults and children said the Museum had met their expectations. Many of these visitors had been prepared by friends, family members, or colleagues who suggested that they visit the Museum (see the quotations below). Several others were already familiar with the Museum, having visited in the past. Two mentioned seeing an advertisement for the Museum which prompted their visit and helped them to know what to expect.

A friend told me that there were some very interesting and strange exhibits here, and also that it was a museum of forensic pathology, so that's what I heard it was and that fits with what I saw. [*male, age 43*]

My parents explained to me what I was going to see, so I had a general idea. They told me what this [Museum] was all about. (What did they say it was about?) The human body and how people get sick and being a doctor. [*female, age 10*]

Slightly less than half of adults and children were surprised by what they saw in the Museum. Many were impressed with the number and nature of the specimens in the exhibition (see the quotations below). A few had expected a larger facility, having visited the Museum when it was located on the Mall. Two others were disappointed that the Museum did not have exhibits about World War I, World War II, and the Vietnam War.

My expectations were to find something about a tenth of this size. (You were expecting a smaller museum?) Yes, but I also knew [the Museum] was [worthwhile] because I'd read that it was a well-kept secret. [*male, age 45*]

(How does what you saw compare with what you thought you were going to see?) Very different. (What did you think you were going to see?) I thought I was going to see a lot of medical instruments and a lot of words I wouldn't understand and more pictures than actual bones. So, it was a lot different from what I thought and a lot more interesting, too. [*female, age 42*]

I thought [the exhibits] were going to be mostly fake stuff. I never thought you could actually see something that was real and [preserved] in water. [*female, age 10*]

Different Reactions to Different Types of Specimens

When interviewees were asked to discuss the different reactions they had to the various kinds of specimens, many interviewees began describing their response to specific specimens. Most of the adults and children talked about the fetal exhibit. For some, the fetal specimens were simply awe-inspiring and emotionally evocative; for others, the specimens were valued on an educational level (see the first four quotations below). A few adults and children also remarked on the hairball and the elephantitis exhibits (see the fifth quotation).

The fetal specimens are amazing, because they were perfectly formed—incredible detail—and of course, when you're looking at a baby fetus, it evokes a certain response. (Can you talk about that a little?) The perfect nature of the lips, the expression on the face—[it is] almost angelic for some of the fetuses. (So, what do you think of a medical museum displaying the fetuses?) I think it's totally informative. It makes you realize how amazing the human body really is and really understand that sometimes in [development] things can go terribly wrong. [*female, age 38*]

I was amazed by the 'Siamese twins'. I have a nursing background, but I've never seen anything like that. (Can you talk a little more about your reaction to the fetuses?) I guess awe. It's also kind of sad. I can't imagine how people would deal with this—how did the mother feel about her child? [*female, age 47*]

The babies were really cool. The 'cyclops' and 'Siamese twins' were really interesting. (What makes them interesting?) I had never seen one. (Any other reason?) Well, they're real and in jars. [*female, age 15*]

Sometimes [the Museum] can be a little shocking for people if it's their first time. I know that the first time I came here, it shocked me a little bit but, overall, I think it's pretty educational and people need to see that this can actually happen. (What kinds of specimens were shocking to you?) The babies were pretty shocking. I don't mean shocking in a bad way, just you don't get to see things like this very often. . . . (What do you think about showing this stuff, especially to kids?) I think it really depends on the maturity level of the child. I think, for some children, it really depends on how their parents raised them, because some of their parents might think that this museum is shocking and it's gross and they shouldn't be here. But then other parents might think it's very educational, and if the parents think that this museum is very educational, then the children will learn more. . . . My mom told me about the Museum and explained to

me why the babies are here. (What did she say?) [The exhibit] shows people that it [developmental abnormalities] can happen and it's not funny. Because maybe when you talk to somebody and you say you saw a baby with one eye, a 'cyclops,' they might start laughing. But then when you actually see it, it's sort of makes you crumble inside. It's like, "Oh God, that really can happen." [*female, age 11*]

(People can have a lot of different reactions as they look at the exhibits. Different specimens can cause different reactions. What would you say were some of your reactions?) Morbid curiosity—just curious about the really unusual and odd [specimens]. It's kind of disgusting but still interesting. (Is that disgusting in a negative way or positive way?) In a good way. (Did you have different reactions to the different kinds of specimens?) Yes, the 'Siamese twins' and the 'cyclops'—the elephantitis stuff—the hairball was pretty interesting, too. (And your reactions were mainly?) Just fascination. (Did you have different reactions to the 'Siamese twins' as opposed to the elephantitis leg?) No, just interest, curiosity. It's really unique stuff. [*male, age 42*]

Instead of describing the way in which different types of specimens elicited different reactions, some adults talked about how individuals' responses might vary. Several emphasized the personal nature of the experience (see the first quotation below). Two others contrasted the reactions of medical professionals with those of the general public (see the second quotation).

I think different people can have different reactions. I think [the specimens] are very graphic and very real, and I think it's absolutely about ourselves—our bodies and mortality. I think that touches people at the very core of their being. I think it's also that people personalize what they see. Some specimens are either real or very real looking, and so people may react in a very personal way to them. I think that we aren't taught that [those] reactions are okay and that it's okay to look at these kinds of things. I mean it's just part of our bodies. [*female, age 46*]

(People can have different reactions to different kinds of specimens. Can you talk a little about the different reactions you had?) I can see if someone is in the medical profession and is used to seeing body parts and infections, [their reaction would be different from] a layman who might react like, "Oh, my God, this is gross." You know what I mean? But looking at it from a rational, open-minded, educational point-of-view, it's gross but it's the real thing. Some people may be taken aback by some of the disgusting stuff, but that's the nature of this museum, that's medicine, that's medical history, and it's appropriate. (Did you have any different reactions to different types of specimens?) More of a reaction? No, not really. [*male, age 40*]

Because interviewees did not initially differentiate their reactions to the various kinds of specimens, they were asked a series of follow-up questions, directly focusing on the issue of whether bones, wet tissue specimens, and models, photographs, and illustrations that show patients' faces elicit different responses [see Appendix B for the post-visit interview guide]. All of the interviewees thought bones were appropriate for display in the Museum. Similarly, all of the adults and all but one child considered wet specimens acceptable for public viewing. In terms of images that show patients' faces, all of the adults and all but one child felt they were

appropriate for the Museum's exhibition, although a few adults said they preferred seeing actual specimens rather than images. Four quotations are provided below to exemplify interviewees' responses.

(Can you talk a little about the different reactions that you had to the different types of specimens?) Nothing bothers me. It's all interesting. (Some people have said that showing bones is okay, but they'd rather not see the specimens in jars. What do you think about that?) Oh, no. I like the jars. I mean, I like all the real stuff, but I think the jars are the best part. (What makes them the best part?) They're just really unique, stuff you never see anywhere else. (What about the models or photographs that show patients' faces? Do you react differently to them than to actual specimens?) I like the models and photos, too, but I like the actual things in jars. It's much neater to see that stuff. [*female, age 46*]

(Some people have said that showing bones is okay, but they'd rather not see the specimens in jars. What do you think about that?) I think both are fine. I'm not a doctor or anything, but I think if you're squeamish, you wouldn't come to this museum. (What about the models or photographs that show patients' faces? Do you react differently to them than to actual specimens?) It's important to have a mix of things. I like seeing the real specimens, but I also think showing people is important. I think seeing the face of the sufferer, like the person with the huge cyst on his nose, really puts back the human element. [*female, age 26*]

(Some people have said that showing bones is okay, but they'd rather not see the specimens in jars. What do you think about that?) I like the stuff in jars. I didn't find it revolting, and I didn't feel like it was undignified. . . . Sometimes it's difficult to tell if something's a model or real, but that's my only complaint about the jars. (What about the models or photographs that show patients' faces?) Sometimes the images are tough to look at, like the Civil War amputations, but that's what happened. The Museum is supposed to tell the truth, not shade the truth. [*male, age 45*]

(Some people have said that showing bones is okay, but they'd rather not see the specimens in jars. What do you think about that?) I think that everybody's seen bones, so it's cool to see them but not really something you'd go all the way to the Museum to see. But I would come here to see the stuff in jars—to learn about diseases and just see something really unique. (What about the models or photographs that show patients' faces?) Yeah, the guy with the huge nose [acne rosacea] is pretty cool. It makes you think about diseases and what happens to the people who get them. [*female, age 12*]

Disturbing Specimens

When asked directly whether they found any specimens disturbing, most of the adults and children did not think anything in the Museum was disturbing. Some of the adults emphasized that visitors to a medical museum should expect to see human remains on display; others thought the word “disturbing” was too negative, preferring to describe specimens as “interesting” or “realistic.” Some children simply thought the specimens were “cool”; while others said the specimens were “gross, but in a good way.”

In contrast, two adults and two children found the fetal specimens disturbing. These interviewees thought the fetal material would be less disturbing if changes were made to the exhibition (see the two quotations below). Two other adults found the hairball “nauseating” and did not understand why it was displayed in the Museum.

The babies were kind of sad, because they couldn’t be born. (Is there anything that could be changed about the exhibit to make it less sad?) No, I think it’s just sad that it [abnormalities] sometimes happen. *My son wanted to know how all the [normal] baby skeletons died. It kind of bothered him that he didn’t know how they died. [*male, age 10 and female, age 40*]

All those babies in jars. They were gross. I found that disturbing. (What about the fetuses was disturbing?) Well, they were in jars. I don’t know. I thought it was kind of sad, that’s all. (Is there any additional information or explanation that could be provided to make them less disturbing?) No, I just think it’s that they were real. It’s just a little disturbing that they’re actually real little babies that were stuffed in jars for people to look at. Maybe it was just the way that they were set up. You had a lively exhibit [about pregnancy] where you go over and try on the [pregnancy] vest and watch the videos. Then, you walk across and you see the sort of innocuous row of children’s skeletons and then you walk through and all of a sudden you are confronted by all these [pathological fetuses]. I mean, I don’t know if it was done [on purpose] since this is a pathology museum, but it certainly took the cuddle, the fun out of childbirth. And I think that’s important, too. [*female, age 26*]

Questions Visitors Had about Specimens

Some interviewees had questions about the specimens they saw in the Museum. A few adults and children were unsure which specimens were “real” and which were plastic models. A few others had questions about the donors of the specimens: “Where does the Museum get its specimens?”, “How did the children die, and how did you get their skeletons?”, and “How did the babies die, and how did the Museum end up with them?”

Educational Mission of the Museum

When asked what the Museum could do to help visitors have an educational experience, nearly all of the interviewees thought that the Museum, for the most part, was already providing this (see the two quotations below).

[The specimens] were really fantastic. I’ll put it to you this way. [My teenage daughter] said, “Biology’s fascinating.” So if somebody her age walks out of an exhibit saying that, isn’t that what it’s all about? [*male, age 45*]

I’m not a medical person, but to me, some of these specimens are just amazing. I’ll never get a chance to be in medical school, like dissection labs and all that, but here [at the Museum] I feel like I’m getting a sneak peak into the medical field—like I’m getting to

see things only doctors usually get to see—and that’s pretty neat. I mean, this is a really unique museum [where] you get to see stuff that you wouldn’t normally get to see.
[female, age 24]

To further promote an educational experience, interviewees had several suggestions. Some adults thought the exhibits needed label text geared to the general public rather than to specialists (see the first quotation below). Others thought the inclusion of additional healthy specimens for comparison with the pathological specimens would also be educational (see the second quotation). A few medical professionals wanted their specialty (e.g., respiratory therapy, cardiology, pharmacology) featured in the Museum. A few other adults and children felt the exhibition should have more health-related topics rather than pathological ones (e.g., detailing common ailments instead of rare diseases) and discuss disease prevention. One adult thought a complete human body model should be included to show the relationships of the individual systems currently featured in the exhibition. Another adult thought the Museum should have an operation exhibit with surgery videos.

[There needs to be] better text, better labeling. I think the exhibits need to be put in context—nothing in [the exhibition] even explains what forensics is. So, [the exhibits] kind of look like a freak show with a scientific veneer on top. . . . I think if the exhibits were explained in a way that wasn’t technical and didn’t assume a lot of sophistication on the part of [the visitor], it could go beyond just being strange or weird. I can give you an example: the exhibit with the sort of exploded view of the skull that shows all the bones of the skull with different nerves. I think that it’s really interesting to give people a real sense of the machine-like level of their bodies. But, there was almost no explanatory material with it. So, it’s something for [a person] to look at and, if they’re really interested or if they can read the long words, maybe they’ll get something out of it. [If] they want to know something quick about [the skull], they’re out of luck. [The Museum] should prepare an attractive bit of text to go along with [the specimens] so that people could understand more about what they were seeing, or so kids could get roped in. . . . There’s obviously an effort to include some of these things, like you have visual aids and videos, but it looks like it’s mostly been prepared for specialists. It’s like you already have to know something in order to be able to relate to it. Otherwise, you won’t [understand it], and that’s a shame. [male, age 43]

I like when [the exhibits] had comparisons between normal to abnormal, because sometimes you weren’t sure what it was supposed to look like, and when you see both, then you could see the difference. If you’re not medical, you’re not sure what you’re looking at. [female, age 45]

Children in the Museum

Overall, the children interviewed and their accompanying parents thought the Museum was appropriate and educational for children. As stated earlier, only two children had negative reactions to the specimens. One of the parents whose child found specimens disturbing, admitted that she should have prepared her child for the experience (see the quotation below). When asked what would improve their visit to the Museum, a few children suggested more computer

interactives, and others wanted the opportunity to talk with a scientist or doctor. A few adults thought more hands-on experiences were needed for children; whereas, others criticized the existing computers and bicycle component for being distracting.

I'm really surprised how negatively she reacted to the Museum. I think this is a great museum, but, I guess, some kids just aren't going to enjoy it. I loved it when I was a kid and [the Museum] was down on the Mall, so I'm surprised that she's so grossed out. (Is there anything the Museum could do to make the experience better for your family?) I wouldn't change it at all. I think some kids just don't like it. I mean there were a number of kids in there who were fine. I think it's kind of my fault. I didn't want to spoil the surprise or her own discovery, but obviously I needed to say something to her [about the exhibits]. [*female, age 38*]

Opinions about the Museum

During the interview, several interviewees questioned why the study was taking place and expressed concern that the Museum would change its exhibitions. As the quotations below show, these adults stressed the centrality of the specimens.

[I think] that some of this stuff is really scary to look at, but I think that that's [a] good thing because it gives people some sense of immediacy. . . . I hope that if [the Museum] overhauls the exhibit, they won't take that stuff out because, there's enough that's sanitized and antiseptic [in the world]. . . . I think it's good to have a direct experience. [*male, age 43*]

It seems like I was here years ago and I remember there was more of that stuff, like the old stuff, the stuff in jars. Seems like you're getting away from that, and I hope not. I mean, I like the gory stuff—that's what makes this Museum unique. [*male, age 53*]

II. FOCUS GROUPS: PRINCIPAL FINDINGS

DEMOGRAPHIC CHARACTERISTICS

A total of 20 individuals participated in the two focus groups. As shown in Table II.1, the genders were evenly split between males and females. The mean age of participants was 46 years, with one-third of participants aged 45 to 54 ($n = 7$). In terms of education level, half of the participants had a Bachelor's degree or higher. Half of the participants also had children between the ages of 10 and 18 years. As Table II.2 shows, three-fifths of participants ($n = 12$) visited natural history museums 2 to 5 times in the last two years.

There were two noteworthy differences between the two focus groups. Half of the participants in the second group were African American; whereas, only one African American was present in the first group. In addition, most of the participants in the second group had children between the ages of 10 and 18 years (7 out of the 10 participants), compared with only a few participants in the first group (3 out of the 10 participants).

Table II.1.
Demographic Characteristics of Focus Group Participants ($n = 20$)

Gender	<i>n</i>
Male	10
Female	10
Age	<i>n</i>
25 - 34	4
35 - 44	5
45 - 54	7
55+	4
Ethnicity	<i>n</i>
Caucasian	14
African American	6
Education	<i>n</i>
High school diploma	2
Associate's or technical degree/certificate	3
Bachelor's degree	6
Graduate degree	5
Other	4
Have children between 10 and 18 years of age	<i>n</i>
Yes	10
No	10

Table II.2.
Visitation to Natural History Museums (n = 20)

Number of Visits in Last 2 Years	n
1 visit	5
2-3 visits	8
4-5 visits	4
6 visits or more	3

OVERALL REACTIONS TO A HUMAN REMAINS COLLECTION

To provide context for the focus group discussion, slides of the Museum were shown, and participants were reminded that the Museum's collection includes human remains.⁴ Participants were then asked to discuss why a museum might collect human specimens and what, if anything, the general public could learn from the display of such collections. After participants expressed their views, a statement, prepared by the Museum about its history and mission, was read.

Reasons for Collecting Human Remains

Both focus groups thought a museum would collect human remains specimens for educational reasons. Most participants emphasized that the collection could be used to educate the general public, but some also acknowledged it could be used for research purposes.

Participants immediately said "education" was the reason a museum would collect human remains. In particular, participants thought a human remains collection could be used to teach adults and children about disease (see the quotations below), as well as to show how the medical field has "advanced over the years." A few participants also mentioned that the collection could be used for "study and research" by scientists.

(Why do you think a museum would collect human specimens?) [To show the] stages of disease, [their] effects on the body. [To] give you a visual of what, for example, a cancerous tumor would look like. . . . *I [think] in some ways it might be more helpful to have an actual real thing to look at [rather] than a plastic model . . . like a real bone as opposed to a plastic cast of a bone. [1]

(Why do you think a museum would collect human specimens?) I guess to educate us . . . [I think the Museum is trying] to make our children, or just make people aware that [disease] is something real, everyday, and to teach them how to deal with it and not to have fear or be scared of it. [2]

⁴ During the recruitment, potential focus group participants were told that human remains specimens from the Museum's collection would be shown and discussed. According to Metro Research, no one reacted negatively or declined to participate after hearing this.

Reasons for Displaying Human Remains

Participants thought the public could learn about the human body and the effects of unhealthy behaviors from seeing human remains specimens. A few also felt that seeing such a collection might encourage children to pursue a medical career.

Both focus groups thought seeing human remains would give them a “better understanding of the human body.” Some stressed that seeing “real” specimens would be much more informative and engaging than seeing pictures in a book. Others thought that diseased specimens, showing the effects of drugs, alcohol, obesity, etc., could be used to prevent visitors, especially children, from engaging in unhealthy behaviors (see the quotation below). A few participants saw an additional benefit for children: they thought seeing human remains specimens might “foster a wider vision of medicine for high school students” and encourage them to study medicine in college.

I guess you always hear what cigarette smoking and alcohol can do to the body, [so visitors] might see a [healthy] liver and then [be] shown a liver that’s been affected by alcohol [with] a description of what it [alcohol] can do to your total health. That’s an educational process. *Especially for high school students who might venture into things that would be detrimental to their health. [2]

REACTIONS TO SPECIMENS

After the Museum staff uncovered 12 specimens from their collection, the facilitator read a description of each one (see Appendix E). Participants were given time to view the specimens and to write down any questions they had about them. A discussion about their reactions was then initiated. After describing their initial impressions, participants were asked to describe whether the natural origin of some specimens affected their response, to identify any specimens they found disturbing, and to compare several pairs of specimens.

Initial Reactions

Overall, both groups were impressed with the specimens, often remarking on their natural origin and wondering about the patients. The first group, however, engaged more readily with the specimens than the second group did, as they asked questions about preservation techniques and were better able to decipher visually complex specimens.

Participants expressed awe in their initial reaction to the specimens. Although both groups mentioned three-dimensional specimens and images, they found the “real” specimens (i.e., the specimens of natural origin) particularly powerful (see the first and second quotations below). Participants were also interested in the stories of the specimens’ donors and the patients depicted in the images (see the third quotation).

(What are your reactions to these specimens?) Incredible. Pretty amazing. To actually see the real human tissue, the brain. To actually see a fetus and these ‘Siamese twins’. I mean, it’s pretty amazing. (Is that a positive “pretty amazing” or a negative “pretty amazing”?) I’d say it’s positive. I also like the picture of the man with syphilis [before]

and after the treatment—what he looks like after the treatment makes me [think about] how far we've come in medicine. *With me, it [the plastinated head section] satisfies a tremendous curiosity [about] what the inside of my head look likes. Now I know. To me it is very amazing. [1]

Wow, my eyes went directly to the baby. *Four months, that baby is [quite] developed, not that small. . . . To me that baby is basically fully developed. *The pictures did not have as much impact at first. When I got up and looked closer at them, then I started to really understand the person [depicted in the image]. But [the pictures] did not strike me like the real concrete thing. [2]

I'm concerned with the survival of these folks. Like the guy with the bullet hole in his head, did he live through that or was that a mortal wound? (That's a good question.) *[The hand with the gunshot wound], didn't they have to amputate that hand? (Yes.) *And the guy with the bullet hole, do you know—(We'll learn more about him later.) If I were in a museum and saw those exhibits, I'd like to know that. (You'd like to know if he survived?) Yes, and how long. *None of them survived. *If he lived a year after that [injury], that's great. And the guy with syphilis, he looks like he fully recovered. So, I'd like to know what happened to them. . . . I have a question about [the Civil War illustration]. I'm curious to know why there isn't any blood around the wound. *Is the tissue peeled back? *Yeah, that's what it looks like. . . . I don't know how he can be sitting there like that. . . . It's an odd juxtaposition when you look at the man's face and then you look at what's behind his face, because he just looks like he's sitting there, casually. I'd like to know more about him. [1]

Despite these similarities, there were striking differences between the two groups. The first group began the discussion by asking questions about the specimens' preservation techniques that were mentioned in the identification labels (see the first quotation below). As the conversation continued, participants in the first group became fascinated with the visually complex, plastinated head section (see the second quotation). In contrast, the second group reacted somewhat negatively to the plastinated specimens, stating that they found it hard to believe that the specimens were of natural origin. Furthermore, they were uncertain how to interpret several of the specimens, including the head section that the first group found so engaging (see the third and fourth quotations).

[Specimen list is read to participants.] Can you explain the plastination? (Yes. Plastination means that the actual tissue was injected with a chemical that preserves it and makes it look like plastic. So it's actually of natural origin. A more extensive description will be presented a little bit later, but it's basically something that's been preserved with chemicals, and it's real.) Can I assume that this is a slice of the brain? (Yes, this is a section. An extremely thin slice.) *Is that brain coated in plastic or is [there] liquid inside [the specimen container]? (That's considered a wet specimen.) [1]

I keep looking at [the plastinated head section]. I think that's the most interesting to me, because they [made] such a thin slice. . . . *I have to agree with [his opinion of the plastinated head section] because of the hair—seeing the hair. (What is it about the hair?)

Again, how well preserved [it is]. *And you know that it was from a real person, a thin section cut right out of the middle of someone's head. It's really amazing to see the outside parts—like of the nose, the face—and then to see the inside. [1]

Even though I know these are actual collections, they still just seem fake to me, like at first when you look at them. . . . (Did you think they looked fake or real?) I think a little bit of both. I mean, it's hard to tell sometimes, they can make things look so real that really aren't. You almost have to be told. Some of the things obviously you know [are real], but [others] I'd question. [2]

[The brain tumor wet specimen] doesn't have much of an impact—it looks like a blob. . . . The plasticized [hand] and [brain] doesn't look real, just because of the coloring, the shine that the plastication [gives] it. Not knowing any difference, I would say it looks like a model, a wax model. . . . [The plastinated head section] is kind of interesting but my first impression of it—it looked [like] a meatloaf inside a turkey, you know [laughter]. You can't tell what it is, where it is [from in the body]. If you do not have [an] understanding of what it is, you have to try to [decipher what you're seeing]. But looking at it, it's just one of those things I would look at and say, "Okay," and walk by. . . . It seems like you [would] have to have an advanced degree in medicine or science to make heads or tails out of [the plastinated head section]. [2]

Reactions to Specific Specimens

As participants continued to discuss the specimens, they began making comparisons among them. In addition, some specimens proved to be particularly evocative for participants: both groups found the fetuses compelling; the first group made personal connections to the brain specimens and head section; the second group had negative associations with the photographs of the man with syphilis.

As participants began to differentiate between the specimens they found compelling and those that they did not, they started to make comparisons among the specimens. For both groups, the brain model was uninteresting in contrast to the unique items directly connected to people (see the first quotation below), and the sheet plastinated brain section was deemed overly complex as compared to the other brain specimens (see the second quotation). Interestingly, participants suggested the pairing of the syphilitic femur with a healthy one to help them interpret their observations (see the third quotation).

I just noticed that when I went up to look at the items on the table, I practically ignored [the plastic brain model]. It's the only one up there that's made out of plastic; everything else has some connection to a real person—either a photograph or actual real tissue. I found [the plastic brain model] to be much less interesting to look at than all the other [specimens]. *I concur. (What about the rest of you?) *I agree with it. *I'd use it in teaching but that's about as far as my interest would go, or my curiosity goes. . . . (Can anyone articulate why you just sort of overlook it?) It's not real. *Commonplace. You could probably see that anywhere. [1]

(Are there any others that even approach how you feel about the model?) [The sheet plastinated brain section]. It was really complex. I believe that it was med student material. (Medical student material?) Yeah. It doesn't appeal to me, and it wouldn't appeal to my 14-year-old. First of all, I couldn't pronounce [the Latin names], and, secondly, it has coloring on it. Whereas, [the transverse plastinated head section] doesn't have labels, but you see the hair on his head and his nose hairs and, even though it's colorized, it's more vivid. *The head section is more realistic. [The sheet plastinated brain section] could just be a pen and ink drawing. [1]

In the case of [the syphilitic femur], I'd like to see a normal leg to see what the differences are. *But it would have to be the same age. *My assumption is that the pock marking [is a manifestation of syphilis], but it would help to [have] something to compare it to. That's why [the sheet plastinated brain section] and [the brain tumor] and [the Civil War illustration] and [the skull with the bullet wound] work—there's something to compare. [The syphilitic femur] didn't have a dramatic effect on me [because] there's nothing to compare [it with]. [2]

The first group also explicitly compared the two fetal specimens; however, both groups found these specimens emotionally charged. Two excerpts are provided to exemplify participants' responses.

For me the most striking difference is between [the conjoined twins] and [the four-month-old fetus]. [The conjoined twins], to me, are sad and it's not very sensitive. I would say that a lot of people would be very upset by it. Because, even if they [had] lived, their lives [would not have been] anywhere near normal. [If the four-month-old fetus were] in a display [it would show] a normal progression. [The conjoined twins], unfortunately [bring] to mind what would have been displayed in freak shows. And I think if you're going to display that, they might be set aside into a separate area where there is a strong warning, "Not for the squeamish of heart." *I guess I look at it from a different perspective. The [conjoined twins] probably didn't have a chance of survival outside the uterus, but [the four-month-old fetus] may have, but it never had that opportunity. And so, I guess to me [the conjoined twins], while it's sad, it's [also] interesting to see what can go wrong when two human cells merge. It doesn't upset me to look at it. When I look at [the four-month-old fetus], I think about what the potential could have been for that one if some human hadn't intervened. *That is an assumption. The [four-month-old fetus] could have been a miscarriage. *That's true, and you're right and there isn't any text with it [like] you would see in a museum. *[When] I look at the formation of [the fetus] at four months, it amazes me. *I can't help but think about what my two children were like [at] four months, when they were that old and I didn't even know them. [1]

[The four-month-old fetus] is what is needed to [change] attitudes. It's not so easy to say, "I want a baby," [and then] to see for yourself what grows inside you, so you can see what could happen if you're not prepared. Because that's a four-month-old baby, for abortions it's food for thought. . . . *Both [the four-month-old fetus] and the [conjoined twins] are fascinating. *For me, it [raises] emotions. It seems like they're talking to you.

The emotion on their face or expression makes you want to understand it more. It looks like they're sweet, it looks like they're struggling, it looks like so many different things. [2]

Participants responded to a few other specimens on a personal level. As noted earlier in this report, both groups wondered about the patient with syphilis who was depicted in the photographs; however, for the second group these images recalled the infamous Tuskegee case (see the first quotation below). Participants in the first group relayed their personal or family history in response to the brain specimens and head section (see the second and third quotations).

I've never been too good in history, but the first things that caught my attention were [the photographs of a man with syphilis]. If this [is] military material, why would they perform the experiment at this Institute, knowing--*And according to this [label], they had a treatment [for syphilis] in the 1890's. . . . *It makes you question—I'm not that good with history and remembering names, but if I remember, Tuskegee airmen were in the 1940s. *They [were promised] the treatment, [but] they weren't given the treatment. That was the whole thing. That was the controversy, that they were promised to have the treatment. [Because of] their nationality [race], they weren't given [treatment] because [doctors] wanted to see, to the extreme, what would [happen] to those guys. So, that is why they used them as guinea pigs. [2]

[The plastinated head section] looks like a picture that was [taken] when I had a stroke—when I had a brain scan of my head and there were spots that showed the damage [from] the stroke. *Like a CT [scan]? Like a slice of the CT [image]? *Yeah, a slice right through the middle of your head. [1]

My father died of brain cancer. You know, that tumor. I mean, there it is. That's what killed my father. That really brings things to reality [for me]. [1]

Natural Origin of the Specimens

Both groups thought the natural origin of the specimens made them more powerful than images. Furthermore, knowing the origin made participants conscious of the specimens' human element. Because of the power the specimens, some in the first group stressed the importance of being prepared before viewing them.

When both groups were asked whether they thought the natural origin of the specimens affected how they responded to them, participants agreed that knowing this fact increased the impact of the specimens (see the first quotation below). They further emphasized that the nature of the specimens made them think about the patients or donors behind the specimens (see the second quotation).

(These specimens are all of natural origin, meaning that they came from real people. Does knowing this change your opinion or how you feel about them?) Absolutely. . . . I compare it with the [brain] model. If you would use the word "model" to me, I wouldn't be nearly as intrigued or interested in what I'm looking at. But knowing that we've got the real organ or tissue or skull. . . . That's me—that's a human being. *It's neater to see

it in real life, because with something like this [model], it's just almost like it's an artist's impression as [compared] to what the real thing looks like. [1]

(Does knowing that these specimens are of natural origin, meaning that they came from real people, change how you think about them?) Yes. *Yeah, you almost wonder about the person. *Yes. . . . I know that there were 'Siamese twins' born in the early 1900s, so I just wonder could the mother have died, or did she have an abortion knowing she was having 'Siamese twins'? [2]

Some participants in the first group were careful to emphasize that they had been prepared to see human remains because of the screener question used in the recruitment process (see Appendix C) and that this was important for their preparation. As the quotation below shows, some participants thought it was the shared responsibility between the Museum and parents to prepare children for viewing a human remains collection. As a follow-up question, participants in the first group were asked whether there are some specimens that simply should not be displayed in a museum. None of the participants agreed with this statement, as one stated, "One of the goals [of the Museum] is education. What part of the human body wouldn't you want to be educated about?"

(You quietly shook your head when I asked that question about whether knowing these [specimens] were of natural origin changes your opinion about how you feel?) No. I knew I was coming looking at things that were human, I was prepared. I mean, if you walk into a museum knowing that you are going to be looking at models, then you are prepared for models. I was prepared for human tissue. . . . They [the focus group recruiters] made sure that I wasn't going to be physically ill when I came into this focus group and they [Museum staff] unveiled those [specimens]. So, no, I was prepared. If I had stumbled in off 16th street and said, "Oh, it's a hot day let me go wandering through here," and not [been] prepared, then somebody might be a little bit disconcerted by the exhibit. (So how do you think you might feel this evening if you weren't prepared?) *I could see where some children would really be repulsed by some real exhibits. *I have a seven-year-old. He'd be going bananas over it. He'd be loving this. *Some would and some would have nightmares over it, and I would not like to see that. *I think that's the responsibility of the Museum—to [provide] a progression up to something like [the conjoined twins]. It's not just out there. There is a story leading up to that. So I don't think the Museum would do that to shock you. (I think you've raised an interesting point. Do you think that the Museum needs to prepare people?) Absolutely. *The name of [the Museum] should [prepare visitors]. . . . You have to go out of your way to go [to the Museum]. *If I were going to take my child there, I would explain to him that this is what we're going to see. (That's kind of what I mean. Whose responsibility is it? Is it up to the parent or is it up to the Museum?) I think it is the responsibility of each. *Yeah. *You know what you're going to see. You know you're going to see a medical field. *And it depends on what type of exhibit is being displayed. It depends on the context, we're seeing this stuff out of context. . . . *Or if they [could] have a brochure that shows [which exhibits are in each] room. So that way you [can] either go through them or avoid them if you've got kids. [1]

Disturbing Specimens

Nearly all of the participants did not find any of the specimens disturbing. Rather, they felt their experience with the specimens was educational.

When asked directly whether any of the specimens were disturbing, only two participants said they were disturbed by the fetal material. One stated religious reasons; the other said, “Five months from then and [the four-month-old fetus] could have been among us. That’s tough to see.” Interestingly, a few participants in the second group reiterated that they felt “angry” about the syphilis photographs because they associated them with the Tuskegee experiments. The remaining participants thought “disturbing” was too strong a word, preferring to characterize their reaction as “heightened awareness.”

Comparisons between Specimens

As participants talked about five designated specimen pairs, their preferences for different specimen types and specific specimens became apparent. Overall, participants found the specimens and the photographs more engaging than the illustration or model. However, participants found meaning only in those specimens that they could visually decipher.

Participants were asked to discuss five predetermined pairs of specimens:

1. Civil War illustration and skull with gunshot wound
2. Photographs of a man with syphilis and syphilitic femur
3. Brain model and plastinated head section
4. Sheet plastinated brain and brain tumor, and
5. Conjoined twins and four-month-old fetus.

In fact, participants mentioned three of the five pairs (1, 4, and 5) on their own. Participants’ reactions to the pairs are presented in the sections below.

The Civil War Illustration and Skull with Gunshot Wound

Most participants in both groups preferred the skull to the Civil War illustration, as they questioned the accuracy of the drawing; others thought the two items worked well paired (see the quotation below). A few participants in the second group took the pairing very literally and were concerned that the gunshot wound in the skull was not on the same side of the head as the one in the illustration.

You don’t know [if the Civil War illustration] is realistic. You don’t know whether it’s true or not, or [if] this artist did what [he] was supposed to do. [Maybe he] just drew a nice picture. I mean with this one [the skull specimen] you really see what the human skull is about. *I like having them together. *It’s just [that] the setting or the facial expression [in] the artist’s rendering doesn’t fit [the situation]. When I look at the hole in that skull, and then look at that picture, the picture isn’t [as] real [as] this [skull] is. *The picture makes you want to see the real thing . . . like a photograph rather than a drawing. *Because I don’t know how long he’s been like that. I don’t know how cleaned up he is. I don’t know if that’s how he’s going to spend the rest of his life. It could be for all we

know, a deathbed pose. There's nothing [in the illustration] that says anything about it—the way the tissue comes away from the skull. It looks to me [that] the gunshot wound may [have occurred from] point blank [range] and it burned away skin. There are so many questions about how it happened and why it looks the way it looks. The skull, on the other hand, there's a hole in the head. It's very definite. There's a hole in the head. There's no question [about] that. [1]

The Syphilis Photographs and Syphilitic Femur

Participants had mixed feeling about the pairing of the photographs of a man with syphilis and the syphilitic femur. Some in the first group complemented the pairing, while others were more interested in the photographs than the bone (see the first quotation). Participants in the second group had difficulty interpreting the syphilitic femur and seeing a clear connection between the specimens (see the second quotation).

The photos show you before and after treatment. [With the bone], we're not seeing the cured bone, so [this comparison] just needs a little more completion to it. The comparison of the [syphilitic] bone to [what is] normal. . . . I think it's much more impressive to see human facial expressions, eyes, face. That has more impact on me than a bone. *I think that they really work together, though. I think if you had just the bones, it would be hard to keep in mind that you're looking at [part of] a human body, so having the pictures and the parts together helps, me anyway, form a full picture of what's going on. *I agree. *It gives it some humanness. [1]

I thought the [photographs] were dramatic. [The syphilitic femur] was difficult to put in a relationship [with] anything. You have to say, "Syphilis did all that [damage] to the bone." I really wasn't quite sure what all that [scaring] was. It could have been a piece of driftwood. . . . [The photographs] were very dramatic, to say the least. (Does seeing the face of the patient in the photographs, make any difference for you?) We're not seeing the thigh bones, so that's the difference. I'm not connecting the thigh bone to the face, so it's kind of not connected. So if they showed his leg, maybe we could make a better connection, but it's just that you're seeing a face and then you're seeing a leg, and it's kind of not connected. It looks like you're showing two different things here. The pictures show the attempted treatments, and you're seeing the face. . . . That's a different issue than what syphilis did internally to the bone. [2]

The Brain Model and Plastinated Head Section

The first group appreciated the pairing of the brain model with the plastinated head section because they enjoyed seeing the "real thing" and thought the brain model could be used to help them "identify" structures seen in the plastinated head section. The second group said the brain model was "elementary" and the plastinated head section was "far advanced." They also reiterated that the head section "does not look like a brain" and suggested that the specimen be "numbered" or have "a color code or schematic to go along with it" to explain the different structures.

The Conjoined Twins and Four-month-old Fetus

Some participants in the first group felt sadness about the conjoined twins, questioning whether they and the four-month-old fetus should be a pair. Others thought the pair demonstrated the miracle of development. An excerpt is provided below to demonstrate the nature of the discussion. The second group associated the conjoined twins with a “chamber of horrors” and “P.T. Barnum” but did not question why the Museum had the specimen in its collection; on the other hand, they were concerned as to how the Museum acquired a “normal” four-month-old fetus. This group then became preoccupied with the preservation techniques and containers of the specimens.

(Are your reactions different to these two specimens?) Yes, they are. . . . I find [the conjoined twins] sad, because I know conjoined twins are born, and I know that a lot of times when they are separated they die or you end up making a choice [about] which one dies. So that whole [idea of] deformity bothers me. [The four-month-old fetus] I look at with awe. It is a wonder to me. *Perhaps they’re not a pair. They’re two separate things. . . . I don’t think they go together as a pair. *I would [agree with feeling] awe for [the four-month-old fetus] and sadness for [the conjoined twins]—how you would separate [them] looks like automatic death to me. Knowing what they are, knowing they’re real, that’s sad. *I guess I just look at it from the perspective. Of all the different combinations of things that could go wrong during the gestational period of humans, it’s amazing that any of us got here normal. I guess comparing [the conjoined twins] to [the four-month-old fetus] does make [the four-month-old fetus] all the more powerful, because it does appear to be normal. . . . Although we don’t know what happened—if it was a miscarriage then there probably was something not quite right. It’s just so amazing to me to think about all the different factors that go into having a baby that’s born normal. And I think [the two specimens] go together to help highlight that. [1]

Sheet Plastinated Brain and Brain Tumor

Both the first and second groups preferred the brain tumor specimen over the sheet plastinated brain. They thought the tumor looked “real,” whereas the sheet plastinated brain “looked made-up,” like a diagram or model. The first group emphasized that the sheet plastinated brain section was too visually complex, with the scientific names labeled on the specimen. Some participants in both groups appreciated being able to compare a healthy brain to one with a tumor, but would have preferred seeing a less complicated, healthy brain specimen.

INTERPRETATION OF SPECIMENS

After participants discussed the specimens, they were asked a series of questions about how the specimens should be interpreted by the Museum. They were then given six interpretive labels on which to comment (see Appendix F).

Information to Accompany Specimens

Participants find comparisons between healthy and pathological specimens useful. Furthermore, they emphasized the importance of having information about current medical advancements and personal information about patients and specimen donors provided.

When participants were asked what kind of information would be needed to encourage them to think about health, medicine, and their body, both groups wanted to see additional comparisons between healthy and pathological specimens. In addition, the first group wanted more emphasis placed on treatments and cures rather than disease, suggesting that the Museum not only discuss history but also current research (see the quotation below). The second group emphasized the importance of giving background information about the patients and donors of the specimens (e.g., Why did the four-month old fetus die? What happened to the man with syphilis?).

For a medical professional, I can see [why] they would need to know a history, how this person contracted this bacteria or disease. But, if [the Museum] is really interested in health and fitness, why not show a lung with tar from somebody smoking? (The Museum is interested in encouraging people to think about health, medicine, and their own body). If the Museum wants to teach to public, show a liver or an alcoholic. (That is part of the Museum's exhibits. . . . I think this is an important issue, does looking at these specimens motivate you to think about health matters and the body, in and of themselves?) No. *No. *This is more a history thing. The Museum probably [goes] from history into the present, or maybe even into the future. . . . I think we're just [seeing] a section of the past here. . . . *We're seeing history here, human tragedy, abnormality, disease, wounds, but what's being done to fix the problem? Like AIDS, is there some long term fix for AIDS, or not? . . . *I think [showing history] gives you the faith that something will be done. For instance, diphtheria, in my time was very real. So to know we don't have that today in western civilization gives me hope for the world. [1]

Responses to Interpretive Labels

Overall, participants responded positively to the interpretive label text. In particular, participants appreciated the personal information about the patients and donors and the description of plastination. For some of the specimens, however, participants thought an explanation of the specimen itself was needed; for other specimens, they felt additional patient information would be helpful.

Copies of the six interpretive labels were given to participants, and the text was read aloud to the groups. Overall, participants were pleased with the type of information presented in the labels. As one participant stated, "Everything that is written satisfies me. They put names with the faces and gave an explanation of plastination. I feel complete now." Participants' comments about individual labels are presented in the following sections. Because of the conversational nature of focus groups, participants only discussed those labels that were meaningful to them.

Plastination Label

Nearly all of the participants thought the label that explained the plastination process was essential to their knowing that the specimens were of natural origin and, as such, to their wanting to engage with the specimens (see the quotation below).

I think it's really helpful to have the information available to people who are visiting the Museum so that they know the answer to the question, "How was this preserved?"
*When I looked at [the hand with the gunshot wound], the hand didn't do anything for me, until now [when I learned about plastination.]. *And for me it's not so much the reason why the preservation [was done], but knowing how the preservation was done helps me believe that this really is a real specimen, not plastic. (And is that important for you?) It is. Otherwise, I would walk through the whole Museum not believing that it was real, and I wouldn't be able to get beyond that to actually look at it and study it and be interested in what I'm really looking at. [1]

Civil War Illustration Label

Participants in the first group appreciated the Civil War illustration label because it "explained the look on [the patient's] face" which had concerned some participants earlier in the discussion. After their initial reaction to the label, participants were asked whether knowing personal information about the patient changes how they think about the artifact or specimen. They agreed that the personal information "humanizes" the content and, although some thought the label was too detailed, overall, they felt the specifics completed the story (see the quotation below). The second group did not comment upon this label.

I think there's a lot of specific details that aren't really necessary for telling a story but including it helps us visualize who that person was and what's going on. (Can you be specific?) *Knowing that he was with Company K, war hero volunteers, that specific detail doesn't influence the fact that he has a head wound. We know that he was in the war, but where it happened and when it happened—I think are details that help give us the full picture. . . . I guess it makes it more real, because you know that somebody did the research, and somebody found out who this person was and what happened. [1]

Syphilis Patient Photographs Label

Participants in the second group thought additional information about the patient was needed, for example, how long the man lived after the mercury treatment and what the side-effects the mercury treatment were. The first group did not comment on this label. However, when asked to compare the information needed for a photograph that shows the patient's face versus that for a specimen like the syphilitic femur, participants thought different kinds of labels were needed. When patients' faces are shown, participants thought personal information was appropriate; for specimens, comparisons between healthy and diseased examples (see the quotation below).

(We don't have any personal information for they syphilitic femur. There's no human face connected—no personal stories. . . . So with an item like this, would that call for a different type of information to make the story complete?) Maybe a description [of] what happened to the bone. What makes it different from a normal bone. *What to look for.

(Do you want to know who's bone it was?) No. I think for specimens, it's too much of a disconnect for people to be able to visualize [that] this [leg] was attached to a whole body and [then] to visualize what that person looked like—[their] name, age, and what caused their injury or illness. *Names go with faces. Names don't go with a bone. [1]

Brain Tumor Label

Both groups were surprised to learn about the origin of the brain tumor. As one participant stated, "I thought it was brain cancer. . . . I didn't realize this was an embryo that never developed [and became incorporated into] the brain of [the other] infant while it was developing. It certainly reaches out and grabs you."

Plastinated Head Section Label

The first and second groups had differing opinions about the label, explaining the origin of the head section. The first group thought it was important to explain where the specimens came from: that people donated their bodies to science and then these bodies were preserved for study. While some participants in the second group thought children would be particularly interested in this kind of information, others reiterated that it was more important to explain how to decipher the actual specimen.

Conjoined Twins Label

Participants in the second group thought the label about the conjoined twins provided a lot of good information. A few wanted to know about "the degree of fusion between the twins." One participant emphasized that the kind of information presented in the conjoined twins label gave him a much better "understanding" and "frame of reference" than the labels explaining the process of plastination. The first group did not comment on this label.

BARRIERS TO VISITING

As the final discussion topic, participants were asked to talk about any barriers they would prevent them from visiting the Museum. Many participants in both groups felt encouraged to visit the Museum after seeing the specimens. Interestingly, participants in both groups made negative comments about the location of the Museum. Others had negative reactions to the Museum's content: some thought the medical subject matter would have limited public appeal, while a few others questioned its appropriateness for young children.

Perceptions of Walter Reed Army Medical Center

Participants in both groups saw the location of the Museum as the primarily barrier to their visiting.

Some participants lamented the fact that the Museum is far from the National Mall and difficult to find, especially for tourists but also for locals. These participants suggested increased advertising and the use of street signs to increase awareness of the Museum. A few participants in the second group thought the Walter Reed Army Medical Center, in which the Museum is

located, was sometimes closed to the public for national security reasons; others who live near the base or had visited the hospital never knew of the Museum's existence.

Appeal of the Museum

A few participants thought that the Museum's medical content would be a barrier for some potential visitors. However, only one participant said that the content bothered her.

A few male participants thought their wives would not visit the Museum because they are "squeamish." When asked if this is a gender issue, most of the women in the group disagreed, stating that the specimens did not bother them. One, however, said that she was somewhat bothered by the specimens (see the quotation below).

I'm not easily grossed out, but when we first went over and looked [at the specimens], my flesh was crawling just a little bit. It's almost like [when] you might pick up a medical book and you start looking through it, and there's always one page that just completely makes you want to shut it and just put it to the side. I think, in small doses this is fine. . . . I think after about half an hour or so, some things would just gross me out, or I wouldn't want to it, schedule it anywhere around lunch. [2]

Appropriateness for Children

Most of the participants who have school-aged children thought the specimens would be appropriate and educational for them. A few questioned whether the Museum was appropriate for elementary school-aged children.

When asked whether they would object to children 10 years of age or older seeing the specimens, most of the participants with school-aged children did not object. In fact, several participants emphasized that they would encourage their child to visit the Museum for educational purposes (see the first quotation below). A few others thought the Museum's target age of 10 years or older may be somewhat too young; others countered this opinion by stating that it depends on the maturity of the child and the context of the exhibition (see the second quotation). Only one participant insisted that her teenage son would be bothered by the fetal specimens.

(The Museum would like to be visited by adults and children 10 and older. What do you think about children 10 and older seeing these specimens?) I think it's a perfect age. At the age of 10, they start questioning about where babies come from and want detail, and they really need to have some kind of reference that will spark their interest to know. . . . I think maybe you [shouldn't] go into so much depth, but just to expose them to this, so when they get older and start developing questions about their body, they have something to think about. And like I said before, prevention. We need to do more prevention. They won't know about certain things until it happens to them. So I think this can be something that really can get them understanding more at an early age. Because they're more advanced than we give them credit for being. Television has shown them a lot of things that we were not exposed to. . . . *I have a 10-year-old boy, and he and his friends—I would have no problem bringing them to see this. I would not have to bring

them there to show them anything in particular, but I think they could enjoy bits and pieces. You know they would pick and choose. They would look at the hand [with a gunshot wound], and they would be intrigued about that because it's weird. It's gross. They would look at the fetuses and the twins. They might even get interested in the brain slice. But I mean there would be bits and pieces. But again, you don't go to a museum to learn everything. If [my son] picks up 3 or 4 things, if he sees what happens on syphilis, maybe he'll remember that. . . . I don't expect the Museum to teach them about life or any of the other things. It's just to try to expose them to humans. I think that's easily appropriate for a 10-year-old without a problem. [2]

(Do you think 10 is appropriate, or do you think it's maybe too young?) Too young, I think. *It depends. You do have some that are more mature at 10 [years old]. . . . *I think 10 would be an appropriate age. *I think 10 would be scared. *Do you? *10 scares me. *My daughter's 11, and when we go to places like this, I always ask questions afterward to see what she actually got out of it. I think she would [talk about] the fetuses and maybe [the Civil War illustration]. (Do any of you have any objections to your child seeing any of these specimens?) No. *I think they're too advanced for a 10-year-old to comprehend or to get any use out of seeing it. Maybe when they're 16, 18 and having classes in science and physics. *[If] they're well presented, in a right atmosphere. . . . The setting might make it [appropriate] for a 10-year-old. [2]

APPENDICES

APPENDIX A

Pre-visit Interview Guide

[Preamble:] Hello. I'm working with the Museum to help them improve their exhibits. Before you enter the exhibits, I'd like to ask you a few questions. It will only take a few minutes of your time and your input would be very helpful. [Once agreement is reached]: thank you.

1. Why did you decide to visit the National Museum of Health and Medicine today?
2. Is this your first visit to the Museum?
[If yes,] What do you expect to see in the Museum?
3. I do not know how much you know about the Museum and its collections, but as you enter the museum, do you have any questions about what you might see?
4. I have a final demographics question: Do you mind if I ask you your age? (Record gender and age.)

I'd like to ask one last thing of you, as you're looking at the exhibits, please write down on this notepad any questions or comments you have. Your questions and comments will really help the museum improve the exhibits. When you leave, please return the pad to me or leave it at the front desk. Thank you.

APPENDIX B

Post-visit Interview Guide

Today we are talking with visitors about what they think of the exhibits. If you have a couple of minutes, I'd like to ask you a few questions. Your input would be very helpful. [Once agreement is reached] Thank you.

1. Do you have an overall reaction to what you saw today?

How does what you saw compare with what you thought you would see here?

2. People can have a range of reactions as they walk through the exhibition. Different specimens (e.g., bones, wet tissue samples, models, photos) may cause different reactions.

Can you talk about the different reactions that you had?

Can you identify a type of specimen that might cause a particular reaction?

What about other specimens—do they cause another kind of reaction?

[If interviewee talks about the specimens in general term, ask]

Some people have said that showing the bones is okay, but they'd rather not see the specimens in jars, what do you think about that?

Others said they'd rather not see the wax models or photographs that show people's faces, how do you feel about that opinion?

3. Of all that you saw today, what image really sticks in your mind? Why do you think that is?

4. Was there anything that you found disturbing? [If yes]: Why do you think it was disturbing?

5. As you were going through the exhibition, did you have any questions or comments about what you were looking at?

6. The staff at the Museum would like for the public to have an educational experience in this Museum. What do you think the Museum should provide visitors so that happens?

7. Are there any questions or issues that you think should be included with the exhibits to improve the overall quality of the exhibits?

Thank you so much for your time.

(Record gender and age.)

APPENDIX C
Focus Group Screener

HELLO MY NAME IS _____ FROM METRO RESEARCH A LOCAL
MARKETING RESEARCH FIRM. WE ARE CONDUCTING RESEARCH WITH PEOPLE
IN THE DC METRO AREA FOR THE NATIONAL MUSEUM OF HEALTH AND
MEDICINE. THE MUSEUM IS INTERESTED IN BROADENING ITS AUDIENCE, AND
WE'D LIKE TO INCLUDE YOUR OPINIONS. MAY I ASK YOU SOME PRELIMINARY
QUESTIONS?

HAVE YOU VISITED TWO MUSEUMS OF ANY KIND OVER THE LAST 2 YEARS?
_____ YES -CONTINUE _____ NO – **TERMINATE**

HAVE YOU VISITED NATURAL HISTORY MUSEUMS AT LEAST ONCE EVERY 2
YEARS?
_____ YES -CONTINUE _____ NO - **TERMINATE**

DO YOU HAVE CHILDREN BETWEEN THE AGES OF 10 AND 18?
_____ YES -RECRUIT 14 _____ NO - CONTINUE

RECORD GENDER - DON'T ASK
_____ FEMALE RECRUIT 14
_____ MALE RECRUIT 14

MAY I HAVE YOUR AGE. IS IT BETWEEN?
_____ 18-24 RECRUIT 2
_____ 25-34 RECRUIT 6
_____ 35-44 RECRUIT 8
_____ 45-54 RECRUIT 8
_____ 55+ RECRUIT 4

WHEN WAS THE LAST TIME YOU PARTICIPATED IN A MARKETING RESEARCH
DISCUSSION?
_____ NEVER-CONTINUE
_____ LESS THAN 6 MONTHS AGO- **TERMINATE**
_____ MORE THAN 6 MONTHS AGO- CONTINUE

ARE YOU CURRENTLY SCHEDULED FOR ANY OTHER FOCUS GROUPS?
_____ YES- SEE SUPERVISOR
_____ NO- CONTINUE

PARTICIPATION IN OUR RESEARCH WOULD INVOLVE YOUR COMING TO OUR FACILITY IN ALEXANDRIA, VIRGINIA FOR A 2 HOUR FOCUS GROUP ON MARCH 9 (OR MARCH 16) AT 7:00 PM FOR WHICH YOU WILL BE PAID \$50.00. SNACKS AND BEVERAGES WILL BE SERVED.

ARE YOU INTERESTED IN PARTICIPATING IN THIS GROUP

_____YES

_____NO

YOU SHOULD BE AWARE THAT THE OBJECTS YOU WILL BE LOOKING AT ARE PART OF THE COLLECTIONS OF THE NATIONAL MUSEUM OF HEALTH AND MEDICINE AND WILL INCLUDE BONES, PRESERVED ORGANS, FETAL AND OTHER MEDICAL SPECIMENS, IMAGES, AND MODELS.

APPENDIX D

Focus Group Script

Thank you all for coming here this evening. I know all of you must be very busy, so I want to thank you for taking time out of your busy schedule.

There is a formal name for this kind of gathering. It is called a focus group. Often it is used in the profit-making sector as a way of understanding how the public thinks about certain products. Essentially, focus groups are used to test public response. Lately, all kinds of organizations have been using this technique to understand public perceptions. The nonprofit organization that we will be discussing this evening is the National Museum of Health and Medicine. Formally, it was known as the Army Medical Museum. It is now known as the National Museum of Health and Medicine and it is located on the Walter Reed Army Medical campus in Northwest D.C.

You have been selected to participate in this discussion because you all visit museums and you also visit natural history museums. Some of you also all have children between the ages of 10 and 18, and others do not. All in all, you represent a segment of the public that the Museum would like to reach.

I am a consultant. I do not work for, nor am I associated with, the National Museum of Health and Medicine. Rather, I have been hired to help the Museum understand how the public responds to its collection. Letting you know that I am a consultant is important because I want us to have a frank discussion. Staff members at the Museum want to broaden their audience and they want to provide those who do visit with the best experience possible, and the only way to know if they are doing that is to talk with those who might visit the Museum. As the Museum plans for the future, your remarks will be extremely helpful. It is my job to solicit your opinions and ideas, to analyze your remarks, and to place them in a framework that will help museum staff members make decisions and plan for the future.

We are tape-recording this discussion because it is the only way I can have an accurate record of our conversation. I respect what you think, and we just want to make sure I don't misunderstand you. This information will be reviewed by me, and conclusions will be presented to my client. All that you say, positive and negative, will help the museum staff develop high-quality programs for visitors. There will be a total of two focus groups—one tonight and one next week.

First I want to show you some slides to introduce you to the Museum. I am showing you these slides because I want you to know that all of the specimens that I will be showing you tonight are presented in a context, and that context is the Museum exhibition hall. To view the specimens in isolation, like you will be doing tonight, is unusual. So as you look at the specimens, keep in mind that their home is a museum exhibition. (Show slides.)

Much of the Museum's collection are human specimens, meaning they have bones, preserved organs, fetal material, and other medical specimens, images, and models.

Why do you think a museum would collect human specimens?

Many museums are in the business of educating the public, or rather, they view themselves as educational institutions.

What do you think the public could gain or learn, if anything at all, from visiting a museum that has human specimens on display in an exhibition?

I think it is useful to share with you the intent of the Museum—why it was started and what it does regarding collections research—just to provide you with some background information.

(Distribute paragraph of text and read aloud)

Okay, now we can turn our attention to the actual specimens. To give you a better idea of what I mean by human specimens, I have several specimens from the Museum's collection with me tonight.

Here are the specimens. As I introduce each one, please be mindful about your initial reaction. In fact, I would like for you to write down what you feel or what you think after seeing each specimen. If a question about the specimen occurs to you, write that down as well. Each specimen has an identification label with a number. I will also give you a few minutes to look at each specimen and read the labels. Please remember that you should not touch the specimens.

(Hand out identification sheets)

Okay, here they are.

Any reactions?

Does anyone want to compare and contrast feelings or thoughts about the different specimens?

What were some of your questions?

[If no one asked about “realness,” especially of the plastinated specimen, ask]

These specimens are all of natural origin, meaning that they came from real people. These are plastinated, meaning that the actual tissue was injected with a chemical that preserves it and makes it look like plastic.

Does knowing that these are of natural origin change your opinion or how you feel?

Which of these specimens, if any, do you find interesting or intriguing?

Which of these, if any, do you find disturbing?

What about the specimens is disturbing [probe for distinction between the type of specimen versus the specimen itself]?

Is there anything that could be displayed with this specimen or that you could be told about the specimen to make it less disturbing or more acceptable?

What, in particular, is important for the Museum to tell visitors about that specimen?

Do you think there are any organs or parts of the body that should not be displayed?

Okay, let's talk about them from a different point of view. Sometimes a certain disease or trauma is shown with models or photographs of a whole person.

How would you say your response to this skull (number 6) is different from your response to this drawing of the skull trauma (number 2)?

What about the photograph of this patient with syphilis (number 3) and this thigh bone that shows the effects of syphilis (number 7). Both are showing the effects of the same disease. Are your reactions different? How so?

Does it make any difference that you can see the face of the patient?

What about your reactions to this model of the brain (number 4) and this head section (number 8). Are they different? How so?

Here is a normal fetus (number 12) and a pathological fetus (number 9). Are your reactions to each different? How so?

Here is a human brain section that has been preserved through sheet plastination (number 1) and a wet specimen (number 5) showing a brain tumor. Compare your reactions to these two. Are they different? How so?

This Museum intends to be for adults as well as for children 10 years and older.

What do you think about children seeing these specimens?

Would you have any objections to having your children see any of these specimens?

Which ones? Why?

When museum visitors first see the specimens on display, they feel a range of emotions and have a number of questions, similar to what happened here this evening. Following this initial reaction, though, the museum wants to help visitors understand and learn from the specimens.

What would need to accompany these specimens to encourage you to think about health, medicine and your body?

Interpreting or presenting information to accompany objects from a Museum collection is an important issue for Museums. I want to share with you a few ideas about what might accompany these specimens to help visitors process and experience the specimens in a meaningful way—from the Museum's perspective.

Present labels.

Okay, what type of information or context provides you with the information that you want?

Does knowing the information provided in any of these labels change the way you think about these specimens?

What, in particular, is important for the museum to tell visitors about when they display these types of specimens?

Now that you have a sense of the collections at the National Museum of Health and Medicine, do you see any barriers to your visiting?

What are they?

In what ways, if any, can they be overcome?

Thank you all for being so attentive and thoughtful. On behalf of the Museum, thank you.

APPENDIX E

List of Specimens

1. Human brain section. The specimen has been preserved through sheet plastinated.
2. Illustration of a Civil War head wound. By Peter Baumgras of the Army Medical Museum. Reproduction.
3. Photographs of man with secondary syphilis, before and after mercury treatment.
4. Model of the human brain. Denoyer-Geppert, mid-1990s.
5. A tumor of the pineal gland of the brain.
6. Male skull with gunshot wound.
7. Syphilitic femur, ca. 1870
8. Human head section. The specimen has been preserved through plastination.
9. Conjoined female twins.
10. World War I gunshot wound to the hand. The specimen has been preserved through plastination.
11. Half of a human brain. The specimen has been preserved through plastination.
12. Normal fetus, 4 months gestation.

APPENDIX F

Interpretive Labels

Specimen #1 & 8

In the 1970s, Gunter von Hagens developed a preservation technique to produce specimens for teaching in medical schools. The technique is called plastination. In plastination, the body parts are first immersed in acetone and chilled to 13 degrees Fahrenheit. The water is then removed from the cells and replaced with a plastic material. After curing, the plastic hardens, and the specimens will not decay and are safe to be handled.

Specimen #2

Private Patrick Hughes, Company K, 4th New York Volunteers, age 23, was wounded in the head at Antietam, Maryland, on September 17, 1862, during Sumner's attack near Dunker's Church. He crawled off the battlefield and was removed to a field hospital near Keeysville, Maryland. The medical reports vary on some particulars of the case. Hughes survived his injury but suffered from poor memory and bouts of giddiness.

Specimen #3

In 1874, Alwyn W. contracted syphilis and was re-infected with the bacterium 2 ½ years later. He experienced no secondary symptoms of the disease until a sudden and severe outbreak of pussy lesions covered his face and arms. The picture on the left was taken in October 1878 twelve days after the outbreak began. The photograph on the right was taken in May 1879 after treatment with mercury began to clear up the symptoms.

Specimen #5

This section of the brain shows a tumor of the pineal gland. The pineal gland regulates waking and sleeping patterns. Although such tumors are often associated with early puberty, this tumor was present since birth. The tumor is composed of the embryonic tissues and formed during fetal development when a small, imperfect fetus became incorporated into this individual's body.

Specimen #8

Plastinated human head section prepared by Gunter von Hagens, the developer of the plastination process. All of von Hagens' specimens are donated to him by volunteers who know how their bodies will be used.

Specimen #9

Conjoined twins are a rare embryological accident and occur in only 1 of 50,000 to 80,000 births. Conjoined twins are the result of the developing embryo failing to successfully split into identical twins. Almost all conjoined twins are stillborn, and those that survive usually die within a few hours. Since 1974 there have been successful surgical separations of conjoined twins. However, the success of these operations depends upon the degree of fusion between the twins.